

# Counseling Parents of Retarded Children

MARIO VALENTE, M.D., Los Angeles

■ *Recently pediatricians have become more interested in the retarded child and his family and have come to realize that they have been ill-prepared to face the many problems that continually arise. A basic understanding of the role of parents and their aspirations, coupled with a knowledge of interviewing, techniques will enable them to face these problems with greater assurance. In addition, a knowledge of the community facilities and resources is necessary. This will entail direct contact with schools, parent groups, state hospitals for the retarded as well as state and local agencies which deal with the retarded.*

ONE OF THE MOST DIFFICULT tasks facing a pediatrician is that of counseling the parents of a retarded child. It is far more painful than counseling the parents of a dying child, for death is irrevocable and final and its wounds will often be healed with time. The diagnosis of mental retardation, on the other hand, often brings with it the specter of chronic sorrow for the parents and a life of disability for the child.

How the pediatrician handles this situation depends upon his experiences in such matters, his understanding of the factors underlying parental feelings and the manner in which they are expressed, and all too often his own personal feelings. Rarely will his training either in medical school or residency have prepared him for the task.

The pediatrician has an important role in the diagnosis and management of retarded children and in the more difficult task of helping parents live with this problem so that they can cope with the crises as they arise during the various stages of development of their retarded child.<sup>1,2</sup>

The two medical specialties most involved in the field of mental retardation, pediatrics and psychiatry, view the problem from different perspectives. By training, the pediatrician considers mainly the organic and developmental factors, the psychiatrist mainly the psychosocial. The pediatrician, trained mainly to treat acute conditions, usually has little interest in the care and management of the retarded child with all the attendant chronic, often unsolvable problems. The psychiatrist, on the other hand, tends to rely too heavily on his training in psychodynamic theory and practice. What is most needed is a happy synthesis of these two approaches in a physician who is not only well trained in the organic aspects of mental retardation but who also has an understanding of the emotional impact of this condition on both the child and his family.

Training programs in both psychiatry and pediatrics are now trying for this synthesis, but in the meantime most practicing pediatricians and psychiatrists have not had the benefit of this new training philosophy.

This paper is based upon ten years' experience by the author in the field of mental retardation,

Submitted April 23, 1971.  
Reprint requests to: M. Valente, M.D., Neuropsychiatric Institute, University of California, Los Angeles, 760 Westwood Plaza, Los Angeles, Ca. 90024.

first in a state institution and more recently in a university affiliated teaching and research center for the mentally retarded. An attempt will be made to outline some general principles for practicing pediatricians. It should be borne in mind, however, that each family unit differs from the next and that its manner of handling this problem depends upon such factors as the stability of the marriage, family ties, religious attitudes, economic status, education, environment and, last but not least, sociocultural factors.<sup>3,4</sup>

Before a pediatrician can discuss the diagnosis and management of a retarded child with the parents, it is important that he reflect upon the hopes and aspirations all parents have for their children.<sup>5</sup> All parents hope that their children will accomplish much more than they as adults were able to accomplish. One can then imagine the shock upon realization that this dream will not come true. Feelings of guilt, shame and despair will arise and the parents will begin to ask questions such as "Why did it happen to me?", and "What did I do wrong?", and they will very often initially blame themselves.<sup>6,7</sup> With time, they will begin to recover from this initial shock and then will begin to ask questions such as "Why?", "Will it happen again?" and, ultimately, the most important of all, "What can be done for my child?". These last three are fundamental questions which a physician must answer over a period of time.

Sometimes the pediatrician will face extreme reactions which can be quite disturbing to him and, at times, will evoke feelings of hostility within him.<sup>8</sup> The parents might begin to blame all members of the medical profession as well as paramedical personnel for their child's problem, and to act in a very hostile fashion. The worst thing that a pediatrician can do in such circumstances is to react in kind. At the other extreme, some parents will react by either denying that any problem exists or by having their child institutionalized and informing both family and friends that he died. Fortunately, these are extremes, and some parents will even sublimate their problem in a most productive and useful way by directing their efforts toward establishing programs for the mentally retarded.<sup>9</sup>

The three fundamental questions mentioned above sum up most of the questions that parents will ask their physician. However, should

the pediatrician believe that, for personal or other reasons, he cannot face this problem, he should feel free to refer such cases to a qualified colleague or to one of the many diagnostic clinics available in most parts of the country.

*"Why?"* There are two facets to this interesting question. The first involves the etiologic factors of the child's mental retardation. It is here that the pediatrician, with his extensive organic and developmental background, is most competent and feels most comfortable. However, even here frustrations can arise, since in many cases the cause of the mental retardation cannot be uncovered even after the most sophisticated workup. Mental retardation which is diagnosed during the first two years of life is often of the most severe and obvious kind and ultimately the most likely to be labelled with a specific medical diagnosis. If it is the kind that does not become obvious until later, it is more likely to be less severe, not so readily apparent on casual observation, and also less likely to be specifically labelled. Even with the most sophisticated and extensive medical workup, a specific cause can be found in only about 20 to 25 percent of all cases of mental retardation.

The other aspect of the "why" question involves the deep-seated anxieties, fears and guilt feelings which all parents who are faced with this problem have in greater or lesser degree.<sup>10</sup> These feelings will involve such matters as difficulties with in-laws and parents who opposed the marriage, doubts about the spouse's genetic background, and doubts about one's own abilities as parents, from the biologic as well as from the psychologic point of view. The physician needs to be aware of these feelings, but he must not interpret them as being the major contributing cause of the child's problem. If he does, he will only aggravate the insecurity that the parents already feel, thereby making it more difficult for himself but for the parents, too, to help the child. A classic example of this mistake is the once quite ordinary use of the term "refrigerated" with reference to parents of autistic children, the epithet carrying with it the implication that autism was the fault of the parents.

*"Will it happen again?"* This is a question that most parents can be expected to ask, particularly if they are young and the mentally retarded child is their first-born. It can be best answered if the

specific medical cause of the condition has been ascertained—phenylketonuria, for example, where the recurrence risk is known to be 25 percent. Without a specific medical diagnosis, however, this becomes a very difficult question to answer.

Details of genetic counseling have been set down most adequately elsewhere.<sup>11</sup> However, even geneticists need to remember some of the basic principles of parental attitudes in the field of mental retardation in order to cope with the complexities of genetic counseling. For instance, at times parents will come to a genetics clinic not so much to find out what the diagnosis is or to ask about the possibilities of recurrence, as to assess blame on either side of the family, to find excuses for not having other children, or even to find a reason for dissolving the marriage.

*"What can be done for my child?"* This is the most important question parents ask. Most pediatricians, however, lack knowledge about community services, special educational programs and public health and social welfare facilities, and find it almost impossible to answer. Physicians in general have a somewhat negative attitude toward mental retardation because of its chronic nature and their feeling that there is nothing that can really be done for such children. Although it is true that there is no cure once the condition has been well established, much can be done to help some of them to lead productive and useful lives within the limits of their capabilities. In evaluating the prospects, one should stress the positive rather than the negative aspects of the child's potential. A program of priorities has to be established, including fundamentals such as toilet training, dressing, and ambulation. Since nursery schools and public schools for the most part will not accept a retarded child who is not toilet trained, this is very often one of the most important training goals. Training in the fundamentals can be accomplished by utilizing the services of public health nurses, occupational, rehabilitation and recreational therapists and many other members of the paramedical professions. Such assistance can be sought from local medical centers, children's hospitals, local mental retardation service boards, and mental retardation regional centers.<sup>12</sup>

The following is a series of important guidelines to keep in mind when discussing the diagnosis and management of a retarded child with the parents.

### *Counseling takes time*

Counseling parents of a retarded child cannot be accomplished in one visit. Since the condition is lifelong, the parents will need advice over a period of years. Each stage of the child's life may present different problems necessitating different approaches and solutions. One reason pediatricians find the needed counseling difficult is that, regrettably, economic considerations are such that they probably cannot spend several hours talking to the parents. Yet extra time spent initially can save much time that otherwise may have to be taken up later in answering questions piecemeal.

In recent years many diagnostic clinics and centers for the study of mental retardation have been established throughout the country. Unfortunately, all too often such centers have produced costly and elaborate workups which are turned over to the parents as a dismaying mass of information, with no provision for any follow-up care. Many such centers have adopted the so-called team approach to diagnosis and management, which though it has many advantages, also has the major disadvantage that there is often no single person to whom the parents can turn for advice and follow-up. Such clinics have been concerned more with placing a label than in helping the parents plan for the future. They have neglected the simple fact that parents cannot digest all the technical data supplied and are often in such a state of shock initially that they do not even hear most of what is being told them. Therefore, follow-up sessions are needed to repeat what has been said before, and to give parents a chance to ask questions.

### *Identify Major Concerns*

In order to communicate effectively, one must learn to listen. The pediatrician must avoid talking too much. The parents must be allowed the chance to ask questions and ventilate their feelings. One of the best ways to identify the major concerns and questions is to find out how much the parents know about the child's condition and what they want for their child. Such information can readily be obtained by asking a few simple questions:

- *At what age level do you think your child is functioning?* This simple question can give the physician an idea as to how reality-oriented the

parents really are. Most parents have a clear grasp of the realities of the situation, and often their assessment will be the same as that of the pediatrician or the psychologist. A very unrealistic answer, on the other hand, indicates that either the parents do not see the gravity of the situation or that they are consciously or subconsciously avoiding reality. In such cases it might be necessary to follow the case carefully over a period of six months to a year to see if the parents become more aware of the child's slow development. One should never compel the parents to face reality when they are not ready to do so, for this will only create hostility and confusion in them and force them to turn elsewhere for help.

- *What do you think the future holds for your child?* The answer to this question will not only give further insight into the parents' reality orientation, but it will also indicate directions to be taken to avoid putting the child into situations which are non-productive or in which he will continually face defeat. The pediatrician will find out, for instance, whether the parents strongly desire to keep the child at home, and if they do he can avoid making recommendations which will oppose that plan.

- *What can we do for your child?* This question will often help identify the major concerns in question, and will also elicit the existence of various problems at home, not only with respect to the child's behavior and the problems surrounding the daily care of the child, but also with respect to some of the feelings the parents might have concerning the child's slow development, and the impact of the child's retardation on the family unit.<sup>13</sup> This is important because any child is part of a family unit, and what he does or does not do affects every other member of that family group. It is well to remember at this particular point that when one talks about counseling parents, one clearly means both parents, not just the mother. In addition, in some cases it may be advisable to include teenage siblings, since the presence of a retarded sibling in their home can have an emotional impact upon them, and also can cause considerable anxiety with respect to future marriage and children.

The physician must avoid simply attaching a medical label and then telling parents there is nothing one can do. Nothing will more certainly

make "shoppers" of parents. Keeping the following points in mind will help in counseling and management:

- *Do what is best for the child.* This requires not only a complete evaluation of the child's potential but also the establishment of clearly defined training goals. Very often parents will need to have a strong guide in the management and care of their retarded child.<sup>14</sup> Occasionally their guilt feelings will lead them to believe that the child should not be disciplined. In those circumstances he may become unmanageable. In more recent years the technique called behavior shaping or operant conditioning has come into prominence, mostly through the efforts of psychologists.<sup>15</sup> Such techniques are now used not only by psychologists but by educators, public health nurses and social workers and they are based upon methods used by many parents in raising normal children—namely, that of rewarding good behavior and punishing or ignoring bad behavior. For this to be effective, however, one must establish a set of clearly defined rewards for clearly defined behavior, based upon the functional capacity of the child.

- *Help parents learn to live with the problem.* Basically mental retardation is a condition the parents can never really learn to accept; and because of this they will, in one way or another, search for the rest of their lives for answers and solutions. Most parents, fortunately, learn on their own what the best solutions are for them, and in so doing they often turn to family members, friends, and members of the clergy for assistance. How they eventually solve this problem depends upon their inner strength as individuals and upon the stability of their marriage. In-laws or other family members, when they enter into the picture, may sometimes give strength, sometime add to turmoil. Regrettably, a retarded child frequently becomes the straw that breaks the camel's back, causing a disintegration of an already fragile marriage.

There may also be social pressures which cause problems within the family. This is particularly true in the case of an upper middle-class professional or executive, who finds the presence of a retarded child in his household detrimental to his social success.

- *Seek help elsewhere.* Unfortunately, the pediatrician in practice does not have the advantages of the team (or multi-disciplinary)

approach through which diagnostic clinics and centers make use of the services of social workers, public health nurses, psychologists, psychiatrists, educators, and physical therapists. Hence they may think it advisable to refer such children to such a center. However, the practicing pediatrician often overlooks the fact that through his long association with the child and the family he has established a closer relationship with that unit than can possibly be achieved by a team. He should, therefore, feel free to take it upon himself to seek help through various social agencies as well as the regional centers which are now being established in many parts of the country to furnish services to retarded children. Such organizations can help him find placements outside of the home, if necessary, and also obtain nursery school placements as well as public school placements for such children.

The psychiatrist can be extremely helpful in dealing with the problem as a whole,<sup>16</sup> particularly when unresolved guilt feelings and conflicts arise within the family. If appropriate, the pediatrician may sometimes also find it wise to refer the family to a member of the clergy for counsel and help.

Parents should be encouraged to join the many parent groups that have been established throughout the country, most of them under the jurisdiction of the National Association for Retarded Children. Often it is very helpful for mothers of mentally retarded children to meet and discuss their mutual problems. Furthermore, such parent groups often have established their own nursery school programs, workshops and school programs for retarded children, all of which can be of great help not only to the parents but also to the pediatrician.

*Don't allow your own feelings to dominate.* All too often a physician will tell the parent what to do with his child, basing his advice upon what he thinks he would do in a similar situation. This has led to the practice, unfortunately still prevalent in some areas of the country, of strongly recommending to parents that their child with Down's syndrome be placed outside of the home immediately after birth. Parents should be given alternatives, with both the positive and negative aspects of each alternative, and then they should be allowed to make up their own minds in light of their own particular needs.<sup>17,18</sup> At no time should the physician literally command the par-

ents to do what he thinks is best. In the last analysis, the major consideration must always be what is best for the child, and although in one family situation it would be detrimental to have the child placed outside the home, in another family which is unable to cope with this problem and which is disintegrating in the face of it, placement of the child outside the home might be the wisest course.

In most families, merely presenting the options is sufficient. But where it is obvious that the family cannot make a decision, an experienced pediatrician might suggest what seems to him the best solution.<sup>12</sup>

*Deal carefully with coping mechanisms.* Regrettably, some parents enjoy infantilizing their child, and this may be for them a necessary coping mechanism to fulfill an inner need. (We see this sometimes not only in mothers of retarded but even of normal children.) Such mechanisms often have to be modified to some degree in order to help the child. However, at times we might be tempted to help a suffering mother by rearranging her life, forgetting that she is probably thriving to some degree upon that suffering. This is particularly true in cases of extreme symbiotic relationships which every worker in this field has seen in the course of his professional life. Attempting to break up such a relationship will very often result in profound disturbance in either one or both of the members of this relationship. Therefore, provided that this relationship does not interfere excessively with the child's well-being, it is best to let it alone.

Even with careful and thoughtful application of the foregoing, the practicing pediatrician unfortunately will not always be successful in the difficult task of counseling parents. Some parents are just not prepared to listen to any advice. They are the "shoppers," who are all too well known to clinics, medical centers and physicians in practice. Sometimes improper counseling in the beginning is at fault, but often it is simply that the parents do not wish to face the realities of the situation, and hope to find some kind of miraculous cure. Unfortunately, at times they end up in the hands of unscrupulous individuals and organizations who promise a lot but produce little.

In conclusion, it should be remembered that a mere medical diagnosis is not sufficient. A diagnostic label looks nice, and is rather satisfying

to us as professionals, and may be even interesting to the parents; but in the last analysis one must remember that we need to do what is best for the child, and this can be best accomplished by helping the parents learn how to live with this problem, plan for the child's future and help him achieve his maximum potential.<sup>12</sup>

## REFERENCES

1. Pearson PH: The physician's role in diagnosis, management of the mentally retarded. *Pediatr Clin North Am* 15:835-859, Nov 1968
2. Wright SW, Tarjan G: Mental Retardation: A Review for Pediatricians. *Am J Dis Child* 105:511-526, 1963
3. Begab JJ: The mentally retarded and the family. In Philips I (Ed): *Prevention and Treatment of Mental Retardation*. New York, Basic Books, Inc, 1966
4. Wolfensberger W: Counselling the parents of the retarded, In Baumeister AA (Ed): *Mental Retardation Appraisal, Education & Rehabilitation*. Chicago, Aldine Publishing Co, 1967
5. Zwerling I: Initial counselling of parents with mentally retarded children. *J Pediatr* 44:469-479, 1954

6. Liberthson E: Helping families live with and for the mentally retarded child. *J Rehabil* 34:24-26, Nov-Dec 1968
7. Miller L: Helping parents cope with the retarded child. *Northwest Med* 68:542-547, 1969
8. Bryant K, Hirschberg JC: Helping the parents of a retarded child. *Am J Dis Child* 102:52-66, 1961
9. Matheny AP, Vernier J: Parents of the mentally retarded child: emotionally overwhelmed or informationally deprived? *Pediatr* 74: 953-959, 1969
10. Mental Retardation: A Family Crisis—The Therapeutic Role of the Physician. Group for the Advancement of Psychiatry, Report #36, New York, 1963
11. Wright SW, Sparkes RS: Genetic Counselling in mental retardation. *Pediatr Clin North Am* 15:905-923, Nov 1968
12. Tarjan G: The role of the primary physician in mental retardation. *Calif Med* 102:419-425, 1965
13. Casse RM: The professional's responsibility in aiding parental adjustment. *Ment Retard* 6:49-51, 1968
14. Zuckerberg AB, Snow GR: What do parents expect from the physician? *Pediatr Clin of North Am* 15:861-870, Nov 1968
15. Bijou S: Behavior modification in the mentally retarded. *Pediatr Clin North Am* 15:969-987, 1968
16. Simmons JQ: Emotional problems in mental retardation. *Pediatr Clin North Am* 15:959-967, Nov 1968
17. Liberthson F: Helping families live with and for the mentally retarded child. *J Rehabil* 34:24-26, Nov-Dec 1968
18. Zuckerberg AB, Snow GR: What do parents expect from the physician? *Pediatr Clin North Am* 15:861-870, Nov 1968

## USE OF PROPHYLACTIC PACING CATHETERS

There are articles on the use of a prophylactic pacing catheter in acute myocardial infarction that conclude, "Why bother? Patients with inferior infarction who develop heart block do well and they don't need you; those with anterior infarction do badly and you can't do anything for them." I think we have passed the point where we have to be extremely discriminating about the insertion of a pacemaker. I submit that one ought to consider the insertion of a pacemaker as the conservative approach today. . . . I think that in a coronary care unit, with an adequate experienced staff, the insertion of a pacemaker is associated with a very low morbidity and certainly an extremely low mortality. It is a very awkward situation to find yourself in, that is, a patient who has developed a heart block and then develops irritability or one who has developed a second-degree heart block with an intermittent third degree and then develops ventricular prematures. You don't know whether the irritability is due to the bradyarrhythmia or to an irritable area in the ventricle, but if you institute therapy (lidocaine or whatever) there is a very real hazard that you'll eliminate this pacemaker focus if there is a third-degree block or cause a third-degree block in a second-degree heart block patient. We don't do things very well at three o'clock in the morning.

I think all these factors lead one to conclude that (given a good team) if you have a patient who develops third-degree block, whether anterior or inferior, inserting a demand pacemaker is a very conservative approach. . . . I say this realizing that what has been said in the literature about the accomplishments in anterior wall infarction may be true. This is a lot better way to go than to try to sit the patient out, introduce Isuprel® and all the rest of these things that are probably associated with a greater hazard than the pacemaker.

—EDWARD GENTON, M.D., Denver  
Extracted from *Audio-Digest Internal Medicine*, Vol. 18, No. 9, in the Audio-Digest Foundation's subscription series of tape-recorded programs. For subscription information: 1930 Wilshire Blvd., Suite 700, Los Angeles, Ca. 90057